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DOES A CUSTODIAL RIGHTS UNDERSTANDING OF THE GDPR JUSTIFY FRAUDULENT MISREPRESENTATION BY SPERM DONORS?

DOV GREENBAUM JD PHD*

INTRODUCTION

The artificial reproductive technologies (“ART”) sector is notoriously under-regulated¹; only a handful of standout jurisdictions worldwide (prominently the U.K.²) offer substantial regulations. This lack of regulation has recently come to the fore due to a number of stories and cases in which sperm donors, or doctors who have assumed the role of sperm donors without consent,³ have abused the trust of the patients who relied upon them.⁴ There seems to be little that patients can do once their trust has been abused, and there is even less that courts are willing to do in these cases, as they are reluctant to assess the value of human life,⁵ especially if that life is otherwise healthy.⁶

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1. *But see*, Michael Ollove, *Lightly Regulated in Vitro Fertilization Yields Thousands of Babies Annually*, WASHINGTON POST (April 13, 2015), [<https://perma.cc/485E-WHG2>].

2. Carlos Calhaz-Jorge et al., *Survey on ART and IUI: Legislation, Regulation, Funding and Registries in European Countries: The European IVF-Monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE)*, 2020 HUMAN REPROD. OPEN (Table 1) (2020).

3. Minyvonne Burke, *Fertility doctor accused of impregnating women with his sperm agrees to pay millions*, NBCNEWS (July 30, 2021), <https://www.nbcnews.com/health/health-news/fertility-doctor-accused-impregnating-women-his-sperm-agrees-pay-millions-n1275535> [<https://perma.cc/P5ZT-YA39>]; Zuri Hoffman, *Woman says doctor used his genetic material for insemination*, MYNBC5 (June 19, 2021), <https://www.mynbc5.com/article/woman-says-doctor-used-his-genetic-material-for-insemination/36770755#> [<https://perma.cc/N66R-CYJ3>].

4. Jody Lynce Madeira, *Understanding Illicit Insemination and Fertility Fraud, from Patient Experience to Legal Reform*, 39 COLUM. J. GENDER & L. 110, 110 (2020); Cheyenne Dunn, *Fertility Fraud and Proposal for Florida Legislation*, 8 CHILD & FAM. L.J. 133, 134 (2020).

5. Sara Weinberger & Dov Greenbaum, *Genetic Technology to Prevent Disabilities: How Popular Culture Informs Our Understanding of the Use of Genetics to Define and Prevent Undesirable Traits*, 15 AM. J. BIOETHICS 32, 32–34 (June 2015); Sara Weinberger et al., *They Chose. . . Poorly: A Novel Cause of Action to Discourage Detrimental Genetic Selection*, 43 AM. J. L. & MED. 107, 107–37 (2017).

6. *Andrews v. Keltz*, 838 N.Y.S.2d 363, 367 (Sup. Ct. 2007).

Singapore alone may have an interesting take on the matter. The Supreme Court of Singapore in the case of *ACB v Thomson Medical Pte Ltd*⁷, ruled that parents have a right to the desire to have a genetic affinity with their child.⁸ When this desire is confounded by outside forces, it can result in a cause of action.⁹ The court awarded damages of 30% of the child rearing costs to the parents, not as a compensation, but rather as damages for a non-pecuniary loss.¹⁰ Would that court have ruled the same way if the parents had a desire for a child possessing a set of genetic traits from a desired sperm donor¹¹—e.g., blonde hair and blue eyes—but then, through fraudulent misrepresentation by a third party (e.g., the donor), the child was born with dark hair and dark eyes? It is unclear, whether the loss of genetic affinity can be stretched to include the loss of desired genetic traits, but it remains a possibility: “To be a parent is increasingly defined as having either produced the gametes or paid for them.”¹² Alternatively, the court had considered hanging the damages on the UK concept of the parent’s loss of autonomy, which would clearly include instances when the parent’s desires for a particular sperm donor were not accommodated, but the ultimately decided against it.¹³

Consider the question from the opposite angle: as a sperm donor who intends to act fraudulently, or at a minimum, simply anonymously, are there technical and legal tools that would allow them to do so without having their identity discoverable? The question, while distasteful, can provide us with the necessary hypothetical to appreciate a number of foundational ethical and legal concepts relating to genetic manipulation in modern society.

7. [2017] SGCA 20, [2017] 1 SLR 918.

8. *ACB v Thomson Medical Pte Ltd and Others* [2017] SGCA 20 “The Court concludes that the Appellant’s loss of “genetic affinity” should be a recognisable head of loss.” <https://www.supremecourt.gov.sg/news/case-summaries/acb-v-thomson-medical-pte-ltd-and-others>.

9. *IVF Baby Mix-up: Woman Suffers Loss of ‘Genetic Affinity’, Gets to Claim 30 per cent of Up-keep Costs*, THE STRAITS TIMES (Mar. 22, 2017, 6:43 PM), <https://www.straitstimes.com/singapore/courts-crime/woman-who-had-ivf-baby-with-a-strangers-sperm-suffers-genetic-affinity-gets> [<https://perma.cc/N3FQ-XTQ6>]. See also *Case Summaries*, SUPREME COURT SINGAPORE, <https://www.supremecourt.gov.sg/news/case-summaries/acb-v-thomson-medical-pte-ltd-and-others> [<https://perma.cc/4TWW-W6Y5>] (“Persons (such as the Appellant) who consciously choose to undergo IVF do so because of a deep desire to experience, as far as it is possible, the ordinary experience and incidents of parenthood. And when, as in the present case, a person has been denied this experience due to the negligence of others then she has lost something of profound significance and has suffered a serious wrong” (citing *supra* note 7 at 129)).

10. *Supra* note 7, at 106, 150.

11. *Id.* at 130, 135 (“The chance to have a family structure which comport[ed] with [their] aspirations’ and their ‘interest in maintaining the integrity of [their] reproductive plans.’”).

12. Jennifer S. Hendricks, *Genetic Essentialism in Family Law*. HEALTH MATRIX 26: 109–122 (2016).

13. *Supra* note 7, at 115.

At its heart, this paper aims to understand what it is about genetic manipulation that causes society to sometimes condone it and sometimes consider it abhorrent. We aim to answer this broader question through seeking out the answer to the narrower question posed above. To wit: recent advances in genetic engineering have raised the possibility of conducting genetic engineering on sperm samples, for any number of potentially valid considerations, including concerns related to off-target gene editing in whole embryos.¹⁴ However, one pitfall that may not have been considered is the ability to hide the identity of a sperm donor who is abusing the system, or who aims to stay anonymous in a world that is increasingly interested in deanonymizing sperm donors.

How so? Paternity is often determined not via whole-genome sequencing,¹⁵ but rather by a quick analysis of a number of highly variable regions across the human genome. In many cases, these regions are the same ones that are employed by the Federal Bureau of Investigations (FBI) in creating genetic fingerprints and profiles of potential criminals: the Combined DNA Index System (CODIS) STR(short tandem repeats) loci, an alphabet soup described herein.¹⁶

A donor who wanted to hide their identity could conceivably employ genetic engineering technology, such as CRISPR, on their sperm sample to mask their identity through altering the genetic sequences at even just a handful of the sites sequenced in the CODIS system.¹⁷ This is not necessarily a difficult or expensive proposition. CRISPR technology is widely held to be

14. Heidi Ledford, *CRISPR Gene Editing in Human Embryos Wreaks Chromosomal Mayhem*, NATURE (June 2, 2020), <https://www.nature.com/articles/d41586-020-01906-4> [<https://perma.cc/5DQF-49Z9>].

15. Amy L. McGuire et al., *Research Ethics and the Challenge of Whole-Genome Sequencing*, 9 NATURE REV. GENETICS 152, 152–56 (Feb. 2008); Katharina Schwarze et al., *Are Whole-Exome and Whole-Genome Sequencing Approaches Cost-Effective? A Systematic Review of the Literature*, 20 GENETICS MED. 1122, 1122–30 (2018).

16. See generally Amany Abdel Hakim Mousa et al., *Short Tandem Repeat Typing Technologies Used in Paternity Testing: A Case Study*, INSTANT J. FORENSIC SCI. (Apr. 2020); see also Sherif H. El-Alfy & Ahmed F. Abd El-Hafez, *Paternity Testing and Forensic DNA Typing by Multiplex STR Analysis Using ABI PRISM 310 Genetic Analyzer*, 10 J. GENETIC ENG'G & BIOTECHNOLOGY 101, 101–12 (2012); *Paternity Testing*, QIAGEN, <https://www.qiagen.com/th/applications/human-identity-and-forensics/human-identification-applications/paternity-testing/> [<https://perma.cc/7RN2-9XEU>] (last visited June 19, 2021).

17. Caitlin Curtis & James Hereward, *Criminals Can't Easily Edit their DNA out of Forensic Databases*, THE CONVERSATION (May 10, 2018, 11:46 PM), <https://theconversation.com/criminals-cant-easily-edit-their-dna-out-of-forensic-databases-96416> [<https://perma.cc/ZZ3G-HX94>] (citing a conversation with Harvard Genetics Professor George Church: “Asked if CRISPR could alter DNA to the extent it would make forensic evidence unusable, Church reportedly told The Telegraph: ‘We could do that today, easily. A lot of it is done by blood and even if you just get a stem cell transplant you have a new identity’”).

relatively straightforward, and kits to conduct your own at-home CRISPR experiments are easily available, even through Amazon.¹⁸

Manipulating CODIS sites in sperm dodges at least one common bullet in the magazine of ethical concerns associated with genetic engineering. Science currently perceives these CODIS sites to be devoid of any functional genetic information,¹⁹ although this could change as we gain a greater understanding of genetics.²⁰ As such, an alteration of one or more of the CODIS STR loci by a putative donor would not necessarily suffer from the same criticisms levied against those who have conducted or intend to conduct genetic engineering on humans. Changing a CODIS STR loci is seemingly a phenotypically benign act whereas seeking to change coding regions of the genome has the potential goal of effecting phenotypic results.²¹ Even in our hypothetical, the manipulation of CODIS sites is not without risk. There remains uncertainties regarding the off-site targeting of various CRISPR systems such that even an attempt to alter non-coding DNA could result in the accidental alteration of coding DNA,²² and there is always a slim chance that manipulating a CODIS site could have heretofore unappreciated consequences.

Of course, our hypothetical may also be moot from the start. In many of the aforementioned newsworthy cases, the sperm donors often have no qualms about lying to or defrauding the potential parents. These individuals might similarly be undeterred by the ethical and moral ramifications of hiding their identities, especially if the system is ostensibly already intended to

18. *DIY Bacterial Genome Engineering CRISPR Kit*, AMAZON, <https://www.amazon.com/DIY-Bacterial-Genome-Engineering-CRISPR/dp/B071ZXW1TW> [<https://perma.cc/QQ6Y-PMWQ>] (last visited June 19, 2021).

19. Henry T. Greely & David H. Kaye, *A brief of genetics, genomics and forensic science researches in Maryland v. King*, 54 JURIMETRICS 43, 52 (2013).

20. David H. Kaye, “Open to Dispute”: CODIS STR Loci as Private Medical Information, FORENSIC MAG., May 28, 2014; Melody R. Hsiou, *The Future of Genetic Testing and the Legal and Ethical Implications of ENCODE*, 7 SETON HALL HEALTH OUTLOOK 40, 40–44 (2013); Nicole Wyner et al., *Forensic Autosomal Short Tandem Repeats and Their Potential Association With Phenotype*, 11 FRONTIERS GENETICS, Aug. 2020, at 1.

21. David Cyranoski, *CRISPR-baby Scientist Fails to Satisfy Critics*, 564 NATURE 13, 13–15 (2018); David Cyranoski & Heidi Ledford, *Genome-Edited Baby Claim Provokes International Outcry*, 563 NATURE 607, 607 (2018); Rodolphe Barrangou, *CRISPR Crossroads for Genome Editing*, 1 CRISPR J. 349, 349–350 (2018); Sean C. McConnell & Alessandro Blasimme, *Ethics, Values, and Responsibility in Human Genome Editing*, 21 AMA J. ETHICS 1017, 1017–20 (2019); Jing-ru Li et al., *Experiments that Led to the First Gene-edited Babies: The Ethical Failings and the Urgent Need for Better Governance*, 20 J. ZHEJIANG UNIV.-SCI. B., 32, 32–38 (2019); Owen Dyer, *Researcher Who Edited Babies’ Genome Retreats from View as Criticism Mounts*, BRITISH MED. J. (Nov. 23, 2018), <https://www.bmj.com/content/363/bmj.k5113.full> [<https://perma.cc/5L6H-CGP8>].

22. Jon Cohen, *CRISPR Offshoot Still Makes Mistakes Editing DNA, Raising Concerns about its Medical Use*, SCI. (Feb. 28, 2019, 2:00 PM), <https://www.sciencemag.org/news/2019/02/crispr-offshoot-still-makes-mistakes-editing-dna-raising-concerns-about-its-medical-use> [<https://perma.cc/3NQB-93H3>].

be anonymous. We will assume then for our thought experiment that the malfeasant sperm donor has a moral code that requires them to be concerned with the manipulation of genetic code—a sort of genetic exceptionalism, if you will.²³

Given these caveats, this paper will examine the aforementioned ethical and legal issues, as well as other related legal considerations that the purveyors of ART may come across when conducting this putative fraud.

In the end, we hope that this hypothetical will not result in more news stories regarding the fraudulent misrepresentation of donors, but simply lead us to a greater appreciation for why society seems to have distinct and dichotomous views when it comes to different types of genetic manipulation.

I. RECENT SPERM DONOR NEWS STORIES

Twenty-one-year-old Londoner Oli Benjamin was born to a lesbian couple that employed in vitro fertilization.²⁴ Oli eventually sought out his biological sperm donor father in California when he turned eighteen.²⁵ Oli's biological father had chosen at some point to no longer remain anonymous.²⁶ After signing up on the US Donor²⁷ Sibling Registry, a non-profit website for donor-conceived people seeking their biological siblings,²⁸ Oli learned that his father has sired at least another twenty-five children, some of whom had no knowledge of the nature of their birth.²⁹

In another case, seven Canadian families sued an ART clinic in Newmarket, Ontario for negligently misleading them as to the source of the sperm used to conceive their children, five of whom have been diagnosed with a degenerative genetic condition, Charcot Marie Tooth disease.³⁰ The disease affects the nerves and can cause the patient to lose the ability to walk.³¹ The families, each seeking approximately four million dollars in damages from

23. Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 J. L., MED. & ETHICS (SPECIAL ISSUE 2) 59, 59–65 (2007).

24. Chris Kitching, *Brit Looking for Sperm Donor Dad Discovers He Has 25 Brothers and Sisters in US*, MIRROR (Oct. 1, 2020, 10:00), <https://www.mirror.co.uk/news/uk-news/brit-looking-sperm-donor-dad-22773085> [https://perma.cc/UX84-M3EA].

25. *Id.*

26. *Id.*

27. *Id.*

28. Wendy Kramer, *Connecting Those in Donor Families: The Relevance of the Donor Sibling Registry*, in ASSISTIERTE REPRODUKTION MIT HILFE DRITTER 415–425 (2020).

29. See Kitching, *supra* note 24.

30. Sarah Rieger, *Sperm Bank Mised Families About Donor's Genetic Disorder, \$30M Lawsuit Claims*, CBC (Sept. 28, 2020, 5:12 PM), <https://www.cbc.ca/news/canada/calgary/families-sue-sperm-bank-1.5742372> [https://perma.cc/S9PQ-M8ML].

31. Ágnes Patzkó & Michael E. Shy, *Update on Charcot-Marie-tooth Disease*, 11 CURRENT NEUROLOGY & NEUROSCIENCE REP. 78, 78–88 (2011).

the clinic, also claim that the donor misled the families as to his academic degrees.³² “The families allege that the donor’s condition is apparent, offering photos of the donor which suggest he suffers from an undisclosed genetic condition.”³³

A forty-nine-year-old Vermont man, known only as Joe Donor, has fathered over 150 children in the United States, Argentina, Italy, Singapore, the Philippines, and the UK—with at least six fathered during the pandemic.³⁴ Although currently anonymous, his anonymity is not assured legally. Joe Donor typically donates directly to the mother—not through professional ART clinics, which often provide assurances of anonymity.

In the 1950s, Barry Stevens’ mother used donor sperm to conceive him. Hundreds of other parents, unbeknownst to each other, did the same.³⁵ The sheer size of this extended family calls into question the concept of donor anonymity that could allow for so many children and the possibility of an incestuous consanguineous relationship.

Another super-spreader in South Africa, fertility doctor Norman Tony Walker, provided sperm for more than a hundred conceptions.³⁶ The sheer number of this doctor’s children was unappreciated until one of his biological grandchildren took a home consumer DNA test that matched her with unknown relatives.

In 2019, Norman Barwin, a Canadian doctor who has been inseminating patients since 1973 and received the Order of Canada in 1997 (the second highest honor for merit in Canada), admitted to professional misconduct by using his own sperm to inseminate at least sixteen patients. Barwin also admitted he used the wrong sperm in at least seventy-five other cases. As a result, Barwin lost his medical license and paid a fine.³⁷

32. See Rieger, *supra* note 30.

33. *Id.*

34. Jessica Green, *Sperm Donor with 150 Children Worldwide Who’s Had Unprotected Sex with Scores of Women Says COVID-19 Hasn’t Slowed Him down After Fathering Six More Babies During Lockdown*, DAILY MAIL (Sept. 30, 2020, 7:48 PM), <https://www.dailymail.co.uk/femail/article-8788861/Prolific-sperm-donor-says-coronavirus-slowed-down.html> [<https://perma.cc/WT93-L6HU>].

35. Barry Stevens, *Finding out I Had 600 Half-siblings Sent Me on a Quest to End Sperm Donor Anonymity*, CBC (Sept. 15, 2020, 5:41 PM), <https://www.cbc.ca/documentaries/cbc-docs-pov/finding-out-i-had-600-half-siblings-sent-me-on-a-quest-to-end-sperm-donor-anonymity-1.5699361> [<https://perma.cc/28EP-XJBS>].

36. Fiona Darroch, *Learning that a Fertility Doctor Was My Biological Father Was Painful – but on the Upside I Have Hundreds of New Siblings*, THE GUARDIAN (Sept. 22, 2020, 2:00), <https://www.theguardian.com/lifeandstyle/2020/sep/22/learning-that-a-fertility-doctor-was-my-biological-father-was-painful-but-on-the-upside-i-have-hundreds-of-new-siblings> [<https://perma.cc/X2ZC-NFAA>].

37. Antoine Trépanier, *Class-action Lawsuit Against Disgraced Fertility Doctor Grows*, CBC (June 15, 2020, 4:00 AM), <https://www.cbc.ca/news/canada/ottawa/norman-barwin-class-action-16-biological-children-1.5609426> [<https://perma.cc/7EK8-6K67>].

However, not all stories feature the donor as a defendant. In September 2020 a British man successfully sued a clinic for using his sperm to inseminate gay couples against his wishes.³⁸ Forty-nine-year-old Neil Gaskall claimed that he was not homophobic but rather that he worried about how the resulting children would “be brought up, whether they’d be bullied in the playground, or about having two mums. I didn’t want that for my children. I accept that’s going to be divisive, but it’s how I feel.”³⁹

In addition, in September 2020, the Supreme Court of Georgia paved the way for couples to sue a clinic for negligence in allowing a donor to misrepresent his credentials.⁴⁰ In partially reversing the lower court’s decision, the Georgia Supreme Court allowed the Norman family to sue Xytex Corporation for selling them the sperm of a criminal lacking the scholarly and academic background they were promised.⁴¹ The donor also passed on a rare genetic disorder, thalassemia minor, to the child when he was conceived in 2002.⁴² Rather than a healthy, 160-IQ, multi-degreed individual, the actual donor (unintentionally disclosed by the clinic as Chris Aggeles) was diagnosed with a number of psychiatric disorders including schizophrenia, narcissistic personality disorder, and significant grandiose delusions, for which he had been hospitalized on more than one occasion.⁴³ The donor, who was used by at least thirty-six couples to sire children, had no college degree at the time he donated sperm, and was also convicted of burglary.⁴⁴ Both the lower courts and the appellate court were loath to allow for a claim of wrongful birth, wherein the parents would have had to argue that their child was better off never having been born.

Professor Dov Fox considers this to be reproductive negligence, confounding the intended procreation,⁴⁵ a potential criminal act that is

38. Rhuaridh Marr, *Sperm Donor Sues Clinic for Helping Gay Couples Have Children*, METROWEEKLY (Sept. 30, 2020), <https://www.metroweekly.com/2020/09/sperm-donor-sues-clinic-for-helping-gay-couples-have-children/> [https://perma.cc/L5FG-7BV2].

39. *Id.*

40. *Norman v. XYTEX CORP.*, 848 S.E.2d 835 (Ga. 2020); Ross Williams, *Georgia Supreme Court Allows Couple to Pursue Case of Sperm Donor ‘Fraud,’* GEORGIA RECORDER (Sept. 28, 2020), <https://georgiarecorder.com/2020/09/28/georgia-supreme-court-allows-couple-to-pursue-case-of-sperm-donor-fraud/> [https://perma.cc/5CP4-PQZV].

41. *Id.*

42. *Id.*

43. *Id.*

44. *Id.*

45. Dov Fox, *Reproductive Negligence*, 117 COLUM. L. REV. 149 (2017).

uncomfortably common,⁴⁶ and for which there is no transparency in the United States as to the extent of the problem.⁴⁷

II. A SHORT HISTORY OF SPERM DONATION

We can extract a lesson from one of the earliest records of sperm donation, as recorded in the Talmud, although it is unclear if the case is a fantastical hypothetical or an actual occurrence. Simeon Ben Zoma, a first century Mishnaic rabbinical figure, ruled that a virgin woman who became pregnant as a result of a seminal emission in a bathtub may still be considered a virgin vis-à-vis marriage to a high priest.⁴⁸ Although this hypothetical remained seemingly outrageous for centuries, later decision-makers of Jewish law sought to use the presumptions within the story as support for their rulings in the area of sperm donations.⁴⁹

Aside from the subsequent apocryphal cases throughout the centuries,⁵⁰ artificial insemination via sperm donation had been attempted on animals for decades prior to human attempts but was only documented in humans at the end of the eighteenth century by Scottish surgeon John Hunter.⁵¹ Practical methods were developed only a century later in Russia by Ilya Ivanovich Ivanoff and Milovanov.⁵²

Current state-of-the-art technology allows for many different methods of sperm extraction⁵³ and introduction, including intracytoplasmic sperm

46. Susannah Baruch et al., *Preimplantation Genetic Screening: A Survey of In Vitro Fertilization Clinics*, 10 GENETICS IN MEDICINE 685 (2008).

47. Dov Fox, *Transparency Challenges in Reproductive Health Care*, TRANSPARENCY IN HEALTH AND HEALTH CARE: LEGAL AND ETHICAL POSSIBILITIES AND LIMITS, San Diego Legal Studies Paper No. 18-327 (2018).

48. Babylonian Talmud, Megillah 15a.

49. Edward Reichman, *The Rabbinic Conception of Conception: An Exercise in Fertility*, 31 TRADITION: J. OF ORTHODOX JEWISH THOUGHT 33 (1996); Fred Rosner, *Artificial Insemination in Jewish Law*, 19 JUDAISM 452 (1970); Avraham Steinberg, ENCYCLOPEDIA OF JEWISH MEDICAL ETHICS (Fred Rosner trans., Feldheim Publishers, 2003).

50. M.D. Mukherjee, IUI INTRAUTERINE INSEMINATION (Gita Ganguly & B.N. Chakravarty eds., 2012); see also Emilio Maganto Pavon, *Henry IV of Castilla (1454-1574). An Exceptional Urologic Patient. An Endocrinopathy Causing the Uroandrogical Problems of the Monarch. Artificial Insemination Attempts (IV)*, 56 SPANISH ARCHIVES OF UROLOGY 245 (2003).

51. W. Ombet & J. Van Robays, *Artificial Insemination History: Hurdles and Milestones*, 7 FACTS VIEWS VIS OBGYN 137, 138 (2015).

52. *Id.* at 139.

53. See, e.g., Victoria Bell, *Hands-Free Vibrating 'Sperm Extractors' With Adjustable Speed and Grip Settings Are Being Used in Chinese Hospitals to Help Donors Who Are Too Embarrassed to Masturbate*, DAILY MAIL (July 24, 2019), <https://www.dailymail.co.uk/sciencetech/article-7280395/Hands-free-vibrating-sperm-extractors-used-Chinese-hospitals.html> [https://perma.cc/PV97-SHBJ]; Jeff Parsons, *The 'Sperm Extractor' Has Been Invented for Men Who Don't Want to Masturbate*, METRO (Apr. 11, 2019, 12:40 PM), <https://metro.co.uk/2019/04/11/sperm-extractor-invented-men-dont-want-masturbate-9168728/> [https://perma.cc/XR4S-FP3Z].

injection (ICSI), intracervical insemination, intrauterine insemination, and in vitro fertilization. Different jurisdictions have a myriad of different rules as to screening, anonymity, paternal rights, and payment options. For example, in Canada, it has been illegal to purchase sperm since 2004.⁵⁴

Sperm donation can be accomplished either privately, through consenting parties and a directed donor or via an institutional third party such as a sperm bank or sperm agency. Many jurisdictions have laws that provide for rights and obligations when sperm is donated through a corporation or via a licensed physician,⁵⁵ but provide no oversight or regulatory controls whatsoever when the donation is between consenting adults without an officiating third-party.

The first institutional sperm bank was started in 1950 at the University of Iowa, which began the process of commodifying the transaction. This industry today, with many niche banks serving specific clientele, has revenues of hundreds of millions of dollars annually.⁵⁶

Demand is high for American and Danish sperm in particular.⁵⁷ The USA is the world's largest sperm donor market—producing 70% or more of the world's supply—partially due to its assumed anonymity and the lack of

54. K. Daniels et al., *Sperm Donation: Implications of Canada's Assisted Human Reproduction Act 2004 for Recipients, Donors, Health Professionals, and Institutions*, 28 J. OF OBSTETRICS AND GYNECOLOGY 608, 608 (2006).

55. See, e.g., *Jhordan C. v. Mary K.*, 179 Cal.App.3d 386, 389 (Cal. Ct. App. 1986) (“In this case we hold that where impregnation takes place by artificial insemination, and the parties have failed to take advantage of this statutory basis for preclusion of paternity [i.e., via a licensed physician], the donor of semen can be determined to be the father of the child in a paternity action.”); *E.E. v. O.M.G.R.*, 20 A.3d 1171, 1172 (N.J.Super.Ch. 2011) (“[T]he termination of parental rights is controlled by statute . . . the Legislature did not intend for this type of procedure [i.e., a private fresh donation without physician intervention] to lead to the termination of parental rights under the New Jersey Artificial Insemination statute *N.J.S.A. 9:17-44*, and therefore the parental rights of the donor in this matter will not be terminated.”); *In re K.M.H.*, 169 P.3d 1025, 1045 (Kan. 2007) (McFarland, C.J., concurring) (“To come under the statute, an unmarried woman must desire to be impregnated by artificial insemination in a procedure by a licensed physician. She could elect to have an anonymous donor from a sperm bank. The statute would bar the donor from the rights of parentage even if his identity were later determined. If the woman elects to ask an acquaintance to be the donor and he agrees, he has no parentage rights unless the parties agree thereto in writing. If the parties agree in writing, the donor is assuming not only the privileges associated with parenthood but the possible financial burden of child support for 18 years or so. The man might feel flattered to be asked to be the donor and even be assured no child support would ever be sought. Without the statute, the donor would likely have no defense to child support claims asserted by the mother or the child. Under the statute, absent an agreement in writing, the prospective mother would truly become a single parent upon a successful pregnancy, having assumed all parental privileges, duties, and obligations to any child born as a result of the artificial insemination.”).

56. Ya'arit Bokek-Cohen & Limor Dina Gonen, *Sperm and Simulacra: Emotional Capitalism and Sperm Donation Industry*, 34 NEW GENETICS & SOCIETY 243, 244-45 (2015).

57. Soo Youn, *America's Hottest Export? Sperm*, THE GUARDIAN, (Aug. 15, 2018), <https://www.theguardian.com/science/2018/aug/15/americas-hottest-export-sperm-fertility> [<https://perma.cc/9TTH-DZWX>].

consistent regulations. Sperm donation is a lucrative business.⁵⁸ The market is estimated to reach \$22 billion dollars by the end of 2021.⁵⁹

In the United States, sperm banks are at least partially regulated by the US Food and Drug Administration (FDA). As per their regulations, for example, a sperm bank can legally destroy sperm donation records after ten years.⁶⁰

III. DONOR ANONYMITY

In Sweden, as well as a growing number of other jurisdictions, sperm donation can no longer be officially anonymous. In the United States, at least, the veneer of anonymity persists.⁶¹ In contrast, in Belgium, the law only allows strictly anonymous donation, except for donors who already know each other.⁶² Similarly, in Canada, although it is no longer spelled out explicitly in the law, the privacy of donor anonymity is tacitly protected.⁶³ However, in France, donor anonymity is absolute, and any breach can result in a 30,000 Euro fine and up to two years' imprisonment. Anonymity is a matter of French policy and cannot be waived even by the donor.⁶⁴ No matter the jurisdiction, even anonymous donors are often tested extensively, and their identities confirmed.⁶⁵

In many jurisdictions, donors often opt for anonymity for any number of reasons.⁶⁶ But anonymity, unless it is nefarious, seems to be a dying trend by law or for practical reasons resulting from an increasing use of direct to consumer genetic testing kits. There is a growing trend to consider an Open

58. Rene Almeling, *SEX CELLS: THE MEDICAL MARKET FOR EGGS AND SPERM* (University of California Press) (2011).

59. *Global Sperm Bank Market Analysis & Opportunity Outlook 2021*, RSCH. NESTER (Apr. 8, 2020), <https://www.researchnester.com/reports/sperm-bank-market/105> [<https://perma.cc/VE32-9AZH>].

60. See 21 C.F.R. § 1271.270 (2016).

61. See Glenn Cohen et al., *Sperm Donor Anonymity and Compensation: An Experiment with American Sperm Donors*, 3 J. L. & BIOSCIENCES 468 (2016).

62. F. Mahieu et al., *Anonymous Sperm Donors' Attitude Towards Donation and the Release of Identifying Information*, 36 J. ASSISTED REPROD. & GENETICS 2007, 2008 (2019).

63. Alison Motluk, *When it Comes to Sperm Donor Anonymity, Canada is Behind the Curve*, CBC (Sept. 30, 2020, 11:45 AM), <https://www.cbc.ca/documentaries/cbc-docs-pov/when-it-comes-to-sperm-donor-anonymity-canada-is-behind-the-curve-1.5744558> [<https://perma.cc/E4NB-XHSF>].

64. *France*, DONOR OFFSPRING EUROPE, <http://donoroffspring.eu/country-reports/france/> [<https://perma.cc/AQ9C-894J>]. Notably, it is less difficult to maintain this anonymity as the French also ban DTC genetic testing. See Eline Chivot, *Why France Should Liberalize Access to DTC Genetic Testing*, CTR. FOR DATA INNOVATION (July 24, 2019), <https://datainnovation.org/2019/07/tests-genetiques-pourquoi-la-france-doit-assouplir-sa-loi-bioethique/> [<https://perma.cc/X468-FKTG>].

65. Cynthia R. Daniels & Janet Golden, *Procreative Compounds: Popular Eugenics, Artificial Insemination and the Rise of the American Sperm Banking Industry*, 38 J. SOC. HIST. 5, 5 (2004).

66. U. Van den Broeck et al., *A Systematic Review of Sperm Donors: Demographic Characteristics, Attitudes, Motives and Experiences of the Process of Sperm Donation*, 19 HUMAN REPROD. UPDATE 37, 48 (2012).

ID donation.⁶⁷ Under this system employed by many sperm banks, the donor agrees to at least one method of contact with the resulting child after the child's eighteenth birthday. The bank is often the mediator of the contact. Other banks might allow for anonymous contact with the child, again mediated through the commercial system. A third option is a full ID disclosure, once the child turns eighteen.

In the United Kingdom, the Human Fertilization and Embryology Authority determined that donor-conceived children should have the right to obtain the identity of the donor once they become eighteen years old.⁶⁸

Even donors who still choose full anonymity risk having their identification disclosed either through a hack of the sperm bank's databases, or as a result of an easy and inexpensive consumer (DTC) testing kit,⁶⁹ available in most but not all jurisdictions.⁷⁰ Many testing services provide methods for users to find related individuals online.⁷¹ With only a little bit of detective work, it is likely that a child of a donor will be able to trace some of their lineage, including their donor father or a close relative.⁷²

Regardless of the wishes of the donor themselves, eventually the donor's identity will leak as leaks have been a constant since the development of modern reproductive technology.⁷³ This is rather inevitable, unless the donor can do something drastic like alter the DNA of their submission.

67. See Joanna E. Scheib et al., *Who Requests Their Sperm Donor's Identity? The First Ten Years of Information Releases to Adults with Open-Identity Donors*, 107 FERTILITY AND STERILITY 483 (2017).

68. *Rules Around Releasing Donor Information*, HUMAN FERTILISATION & EMBRYOLOGY AUTH., <https://www.hfea.gov.uk/donation/donors/rules-around-releasing-donor-information/> [https://perma.cc/H3M7-48GB]; Craig Niederberger, *Re: Sperm Donor Anonymity: A Concept Rendered Obsolete by Modern Technology*, 200 J. UROLOGY 482 (2018).

69. Meghana Keshavan, *Consumer DNA Tests Negate Sperm-Bank-Donor Anonymity*, SCI. AMERICAN (Sept. 12, 2019), <https://www.scientificamerican.com/article/consumer-dna-tests-negate-sperm-bank-donor-anonymity/> [https://perma.cc/TCW8-B6F3].

70. See generally Dov Greenbaum, *From the U.S. Army to Marriage in Israel: The Legal Status of DNA Testing Kits*, CTECH (Oct. 1, 2020, 9:54 AM), <https://www.calcalistech.com/ctech/articles/0,7340,L-3777436,00.html> [https://perma.cc/78J7-G9GV].

71. See Mary A. Majumder et al., *Direct-to-Consumer Genetic Testing: Value and Risk*, 72 ANN. REV. OF MED. (forthcoming Jan. 2021).

72. Emily Chung et al., *Donor-Conceived People Are Tracking Down Their Biological Fathers, Even If They Want to Hide*, CBC NEWS (Jan. 25, 2018, 5:00 AM), <https://www.cbc.ca/news/science/sperm-donor-dna-testing-1.4500517> [https://perma.cc/GK5E-RD64]; Rhiannon Williams, *Home DNA Testing Kits Are 'Clear Threat' to Donor Anonymity, Fertility Regulator Warns*, I NEWS (Jan. 1, 2020, 12:01 AM), <https://inews.co.uk/news/technology/home-dna-testing-kits-clear-threat-to-donor-anonymity-fertility-regulator-warns-380324>; Ashley Fetters, *Finding the Lost Generation of Sperm Donors*, THE ATLANTIC (May 18, 2018), <https://www.theatlantic.com/family/archive/2018/05/sperm-donation-anonymous/560588/> [https://perma.cc/4BQ5-ST5W].

73. See A.T. Gregoire & Robert C. Mayer, *The Impregnators*, FERTILITY & STERILITY, Jan.–Feb. 1965, at 130.

IV. GENETIC ANONYMITY

Donor anonymity is dying, if not already dead, in part because there is little to protect one's identity once one's genome or the genome of a close relative is publicly available for analysis through one of the myriad online databases of genetic information.⁷⁴

This is not new. Genetic anonymity has been under siege for a long time.⁷⁵ It is unclear how anyone could expect that a set of data points that unswervingly identifies you uniquely could ever be fully anonymized. Even if one personally has never disclosed one's genetic information, some relative has.⁷⁶ With the donor-conceived child carrying around a version of the donor's genome as half of their own genetic complement, it is not hard for a donor-conceived child to find related DNA to test.

A paper by the Erlich Lab at Columbia University showed that it will soon be possible, given the growing pervasiveness of at-home and public genetic testing, to locate at least the third-degree-relative of any Caucasian in the United States,⁷⁷ and from there it is usually possible to identify the actual donor through a bit of sleuthing. Other populations may (currently) be significantly less represented in the genomic databases.⁷⁸ While this research has clear repercussions for the world of policing, it likely also ends any promise of anonymity for sperm donors.

If DNA identification through STR markers such as those in the CODIS system is the kryptonite of donor anonymity, perhaps it can be used as a shield to protect it, as well. Consider the possibility of editing those STR markers in the DNA of a donor's submission such that it is no longer traceable to the donor themselves, to a third-party, or even to anyone.

74. Keshavan, *supra* note 69; see Ricki Lewis, 'The Broken Promise of Anonymity?' *Bioethicist's Call to Guard Identity of Sperm and Egg Donors Is Misguided*, GENETIC LITERACY PROJECT (Apr. 30, 2019), <https://geneticliteracyproject.org/2019/04/30/the-broken-promise-of-anonymity-bioethicists-call-to-guard-identity-of-sperm-and-egg-donors-is-misguided/> [<https://perma.cc/8WZ3-XL89>].

75. Dov Greenbaum et al., *Genomic Anonymity: Have We Already Lost It?*, AM. J. BIOETHICS, Nov. 17, 2008, at 71; Dov Greenbaum et al., *Genomics and Privacy: Implications of the New Reality of Closed Data for the Field*, PLOS COMPUTATIONAL BIOLOGY, Dec. 2011, at 1.

76. Megan Molteni, *Genome Hackers Show No One's DNA Is Anonymous Anymore*, WIRED (Oct. 11, 2018, 2:04 PM), <https://www.wired.com/story/genome-hackers-show-no-ones-dna-is-anonymous-anymore/> [<https://perma.cc/ZZ4K-NH2R>].

77. Yaniv Erlich et al., *Identity Inference of Genomic Data Using Long-Range Familial Searches*, SCIENCE, Nov. 9, 2018, at 690.

78. See Said Ismail, *Arab Population Missing from Global Genomics Database: Expert*, GULF TIMES (Oct. 5, 2020, 9:05 PM), <https://www.gulf-times.com/story/674587/Arab-population-missing-from-global-genomics-datab> [<https://perma.cc/HB5X-46H8>].

V. CRISPR

This next generation technology in biology has been described as a perfect storm of many breakthroughs in DNA engineering. One of those breakthroughs is the ability to direct DNA mutation or changes to very specific areas of the genome.⁷⁹

Even though DNA editing tools have been around for decades⁸⁰ they have been unwieldy, crude, imperfect, and incapable of being used extensively on live subjects until the advent of CRISPR and similar modern editing technologies emerged.⁸¹

Genetic engineering is a form of technology that allows the user to modify the genetic information in an organism. The CRISPR version of genetic engineering, stemmed from decades-old research done initially on yogurt,⁸² the competing research groups of Jennifer Doudna and Emmanuelle Marie Charpentier⁸³ as well as Feng Zhang⁸⁴ only relatively recently discovered the potential role that the bacterial proto-immune system comprising Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) and the endonuclease Cas9 could play in targeted genetic engineering.⁸⁵

The CRISPR/Cas9 system and its numerous progeny⁸⁶ have birthed thousands of research papers and even more projects and have shown the increasingly effective ability of scientists to manipulate human genomes with a specificity. This can metaphorically be compared to the ability to cut and paste within a word processing document.⁸⁷

79. Drew Endy, *Foundations for Engineering Biology*, NATURE, Nov. 2005, at 449; see Linda J. Kahl & Drew Endy, *A Survey of Enabling Technologies in Synthetic Biology*, 7 J. BIOLOGICAL ENG'G, no. 13, 2013, at 1.

80. Tod M. Woolf et al., *Therapeutic Repair of Mutated Nucleic Acid Sequences*, NATURE BIOTECHNOLOGY, Apr. 1, 1998, at 341; Almudena Fernández et al., *A History of Genome Editing in Mammals*, MAMMALIAN GENOME, June 6, 2017, at 237; Mauricio Rocha-Martins et al., *From Gene Targeting to Genome Editing: Transgenic Animals Applications and Beyond*, ANAIS DA ACADEMIA BRASILEIRA DE CIÊNCIAS [ANNALS OF THE BRAZILIAN ACADEMY OF SCIENCES], Feb. 26, 2015, at 1323.

81. Dana Carroll, *Genome Editing: Past, Present, and Future*, 90 YALE J. BIOLOGY & MED. 653 (2017).

82. Kerry Grens, *There's CRISPR In Your Yogurt*, THE SCIENTIST, Jan. 1, 2015, at 1.

83. See generally Jennifer A. Doudna & Emmanuelle Charpentier, *The New Frontier of Genome Engineering with CRISPR-Cas9*, SCI., Nov. 28, 2014, at 1077; Samuel H. Sternberg et al., *DNA Interrogation by the CRISPR RNA-guided Endonuclease Cas9*, NATURE, Mar. 2014, at 62; Lei S. Qi et al., *Repurposing CRISPR as an RNA-Guided Platform for Sequence-Specific Control of Gene Expression*, 152 CELL 1173 (2013).

84. Patrick D. Hsu et al., *Development and Applications of CRISPR-Cas9 for Genome Engineering*, 157 CELL 1262 (2014).

85. Jon Cohen, *The Birth of CRISPR Inc.*, SCI., Feb. 17, 2017, at 682.

86. Caroline M. LaManna et al., *Sharing the CRISPR Toolbox with an Expanding Community*, THE CRISPR J., Jan. 29, 2020, at 248.

87. Janice S. Chen et al., *Enhanced Proofreading Governs CRISPR-Cas9 Targeting Accuracy*, NATURE, Oct. 19, 2017, at 407.

In a highly controversial experiment, it was shown that the technology could be employed to edit the genomes of embryos such that they could be modified to lack a particular cellular receptor (CCR5) associated with the transmission of HIV.⁸⁸

Despite all the controversy associated with CRISPR and gene editing in general, research in this field marches forward.⁸⁹ This easily available and easy to use technology could be used to mask the identification of a sperm donor, as we describe herein.

VI. RIGHT TO KNOW WHO YOUR PARENTS ARE/RIGHT TO MASK WHO YOUR OFFSPRING ARE

A conscientious sperm donor who values their privacy and anonymity may need to balance their needs and rights against those of the future donor-conceived child who may have many reasons for desiring to know who his or her father is.⁹⁰

Is there a right to know who your parents are that needs to be balanced with the desire for anonymity in sperm donors, or even against parents who do not want their children to fully know their origins? Many of these fights have already been fought in the adoption arena where adopted children are increasingly finding it easier to determine their biological birth parents.⁹¹ Admittedly, this analogy is not fully apt—as the adoption process potentially carries less stigma than that of donor conceived children in many cultures.⁹²

A right to know does not only serve those donor-conceived children who want to know the identity of the father, but also the sperm bank clients who deal with companies that are otherwise shielded from negligence and

88. Antonio Regalado, *EXCLUSIVE: Chinese Scientists Are Creating CRISPR Babies*, MIT TECH. REV. (Nov. 25, 2018), <https://www.technologyreview.com/2018/11/25/138962/exclusive-chinese-scientists-are-creating-crispr-babies/> [<https://perma.cc/6W3W-A6P8>]; Henry T. Greely, *CRISPR'd Babies: Human Germline Genome Editing in the 'He Jiankui Affair'*, J. L. & BIOSCIENCES, Aug. 13, 2019, at 111.

89. See, e.g., Heidi Ledford, *CRISPR Treatment Inserted Directly into the Body for First Time*, NATURE, Mar. 5, 2020, at 185; Sharma, G., Sharma, A.R., Bhattacharya, M., Lee, S.S. and Chakraborty, C., 2020. CRISPR/Cas9: A preclinical and clinical perspective for the treatment of human diseases. *Molecular Therapy*; Filipe V. Jacinto et al., *CRISPR/Cas9-mediated genome editing: From basic research to translational medicine*, 24 J. Cellular and Molecular Med. 3766, 3766–78. (2020); Karen Weintraub, *Despite Controversy, Human Studies of CRISPR Move Forward in the U.S.*, Sci. Am. (Aug. 13, 2019), <https://www.scientificamerican.com/article/despite-controversy-human-studies-of-crispr-move-forward-in-the-u-s/> [<https://perma.cc/F7WG-MG7H>].

90. A. Ravelingien et al., *Donor-Conceived Children Looking for Their Sperm Donor: What Do They Want to Know?*, 5 Facts, Views & Vision in ObGyn 257, 257–64 (2013).

91. Naomi Cahn, *Do Tell! The Rights of Donor-Conceived Offspring*, 42 Hofstra L. Rev., 1077, 1077 (2014).

92. Astrid Indekeu & Claudia Lampic, *Perceptions of donor-conceived families: a survey study on the perspectives of teachers*, FAMILIES, RELATIONSHIPS AND SOCIETIES (2021).

accountability by the anonymity of their donors. How can one know if one's sperm donor is really who they say they are if there is anonymity?

In the United States, no matter how you couch the importance of a right to know, as non-state actors, sperm banks cannot be compelled to provide data regarding their clients' identities unless a law is specifically written as such. There is no constitutional 'right to know' that would require sperm banks to provide the identification of their donors. Moreover, anyone suing a sperm bank for identifying information on the donor would likely lack the necessary standing due to the attenuated causal link between the actions of the bank and any potential harm that might be caused by the anonymity of the donor.⁹³

Any legislated right to know—for example, as legislated in Utah,⁹⁴—might result in different bundles of rights and obligations depending on the jurisdiction.⁹⁵ In contrast to the American position, a regional German appellate court ruled in 2013 that donor-conceived children have a right to know who their biological parents are. In Germany, files from tissue donors must be held for thirty years.⁹⁶ Similarly, Israel has been considering allowing donor-conceived children to learn of their biological fathers for some time.⁹⁷ In China, where sperm donation is regulated,⁹⁸ secrecy and anonymity are not legislated but are inherent in the social fabric of society.⁹⁹

Professor Sivan Tamir argues that there is an ongoing ethical obligation that binds all sperm donors to disclose their identities to their conceived children due to various social responsibilities.¹⁰⁰ Professor Tamir equates the

93. Aliya Shain, *A Veil of Anonymity: Preserving Anonymous Sperm Donation While Affording Children Access to Donor-Identifying Information*, 19 CUNY L. Rev. 313, 327 (2015).

94. H.B. 249, 2015 Gen. Sess. (Utah 2015).

95. Marianne Brower Blair, *The Uniform Adoption Act's Health Disclosure Provisions: A Model That Should Not Be Overlooked*, 30 FAM. L.Q. 427, 427 (1996).

96. Marcus Lütticke, *No Anonymity for Sperm Donors*, *Court Rules*, Deutsche Welle (July 2, 2013), <https://www.dw.com/en/no-anonymity-for-sperm-donors-court-rules/a-16582786> [<https://perma.cc/HVL7-MJJP>].

97. Ido Efrati, *Israel Mulls Allowing Some Kids Born of Sperm Donations to Learn Biological Father's Identity*, *Haaretz* (June 28, 2017), <https://www.haaretz.com/israel-news/premium-israel-mulls-allowing-some-kids-born-of-sperm-donations-to-learn-dads-id-1.5489957> [<https://perma.cc/EC8V-WYVF>]; Naomi Mei-Ami, *Background Paper on Sperm Donation in Israel*, Knesset, Presented to the Comm. Rights of the Child, (2005) (Isr.), <https://m.knesset.gov.il/EN/activity/mmm/me01527.pdf> [<https://perma.cc/3JHM-H9P7>] ("In the opinion of Rabbi Dr. Halperin, in decisions on this issue the right of the donor to privacy must be weighed against the more basic right of the progeny to know his identity. Appropriate efforts to ensure the welfare of the child represents one of the expressions of human dignity. In weighing the rights, the right of the minor takes precedence.").

98. Juhong Liao et al., *The Ethical Debate on Donor Insemination in China*, 20 *Reprod. Biomed.* Online 895, 896–97 (2010).

99. *Id.*

100. Sivan Tamir, "Obligated Aliens": Recognizing Sperm Donors' Ethical Obligation to Disclose Genetic Information, *Kennedy Ins. of Ethics J.*, Mar. 2013, at 19.

obligations to disclosure to those who transmit an infectious disease and the donor who transmits their genes.

A knowing negligent transmission of a disease is a prosecutable offense in some jurisdictions,¹⁰¹ and a civil cause of action in many others.¹⁰² There are numerous jurisdictions where the failure to disclose HIV status, even if the exposed partner never becomes ill, is justification for a civil lawsuit and even a criminal charge of criminal sexual battery. Courts, in balancing speech and privacy rights, have often sided with the victim who may have been exposed.¹⁰³ Courts have also found that one does retain a constitutional right to privacy when not engaging in sexual activity that could put someone at risk.¹⁰⁴

However, while powerful, the idea that everyone has the right to know their medical history and the possibility of down-the-line genetic diseases does not always necessitate disclosure. Thus, while it used to be that may not be privy to this information without knowing your parents, much of this data is now determinable from genetic testing either through a medical practice or even an at-home kit.

One can also look to the need to disclose COVID-19 status as a more modern analog to HIV status. In contrast to HIV, it is not clear that there are laws that require individuals to disclose their COVID-19 status. However, the Health Insurance Portability and Accountability Act (HIPAA) does allow covered entities to disclose COVID status to law enforcement, paramedics, and first responders.¹⁰⁵

101. *In First, Israeli COVID-19 Carrier Indicted for Attending Rave, Despite Diagnosis*, Jewish News Syndicate (Oct. 5, 2020), <https://www.jns.org/in-first-israeli-covid-19-carrier-indicted-for-attending-rave-despite-diagnosis/> [<https://perma.cc/EL9R-LM6H>].

102. *See, e.g., John B. v. Superior Ct.*, 137 P.3d 153 (Cal. 2006).

103. *State v. S.F.*, 483 S.W.3d 385 (Mo. 2016) (“Although the statute may compel individuals with HIV to disclose this information under certain circumstances, the burden on speech is incidental to the conduct the statute seeks to prohibit and does not violate constitutional provisions protecting the freedom of speech. Furthermore, the right to privacy does not permit Defendant to expose others to HIV in the course of sexual activities without first securing their knowing consent to such exposure.”); *State v. Batista*, 91 N.E.3d 724 (Ohio 2017) (“R.C. 2903.11(B)(1) regulates conduct, not speech, it does not violate the First Amendment to the United States Constitution, and it is rationally related to the state’s legitimate interest in preventing the transmission of HIV to sexual partners who may not be aware of the risk and therefore does not violate the Equal Protection Clauses of either the United States or Ohio Constitutions.”).

104. *Burch v. Saleh*, No. 3: 20-CV-00028-NJR at 3 (S.D. Ill. May 8, 2020) (“The Supreme Court has recognized a constitutional right to information privacy under the Fourteenth Amendment . . . which includes the protection of medical information concerning an individual’s HIV-status from unjustified disclosures by governmental actors.”).

105. Dep’t of Health and Hu. Serv. of the U.S. Off. for C.R., *COVID-19 and HIPAA: Disclosures to law enforcement, paramedics, other first responders and public health authorities* (Mar. 24, 2020), <https://www.hhs.gov/sites/default/files/covid-19-hipaa-and-first-responders-508.pdf> [<https://perma.cc/JFH8-GS75>].

VII. CRISPR ON SPERM

Labs have begun proposing using CRISPR on sperm to achieve genetic engineering goals.¹⁰⁶ In 2019, it was shown to be possible to employ CRISPR technologies to edit the DNA within sperm.¹⁰⁷ Given the growing concerns with anonymity as described above, we might soon see as the technology progresses, the manipulation of sperm DNA in an effort to maintain that anonymity.

This manipulation would include changing non-coding DNA such that one or more of the CODIS STR markers used in paternity testing could be manipulated to mask the identity of the donor, since paternity is determined through the matching of CODIS markers in the respective genomes of the father, mother, and child.¹⁰⁸

Like the manipulation of embryos, the genetic manipulation of sperm could raise a number of ethical and legal concerns. It should be noted, however, that there are numerous ‘natural’ ways for the father to alter the genetic complement within the sperm—not to mention other methods of affecting the general health of the sperm—without employing any genetic engineering.¹⁰⁹ It is unlikely that a sperm donor/father would be held to task for any of these other types of manipulations. Are genetically engineered mutations that much worse?

VIII. SPERM DONOR LYING

If a sperm donor could technically, legally, and ethically alter their own sperm to mask their identity, would they be required to inform the clinic of their genetic experimentation? If so, would they be required to provide the clinic with their true identity, thus negating their efforts to employ technology to mask their identity?

106. D. Choi et al., *Feasibility of Gene Knockout in Human Sperm Cells Using CRISPR-Cas9*, 110 FERTILITY & STERILITY e301(2018).

107. June Wang, B.A. et al., *A Step Toward Gene Remodeling of Mammalian Spermatozoa by CRISPR-Cas9*, 112 FERTILITY & STERILITY e262 (2019).

108. Efthymia Karantzi et al., *The Effect of FBI CODIS Core STR Loci Expansion on Familial DNA Database Searching*, 43 FORENSIC SCI. INT’L: GENETICS 102, 129 (2019).

109. Paul R. Brezina et al., *Effects of Pharmaceutical Medications on Male Fertility*, J. REPROD. INFERTILITY, Jan.-Mar. 2012, at 3; Simon J. Newkirk et al., *Intact piRNA Pathway Prevents L1 Mobilization in Male Meiosis*, 114 PROC. OF THE NAT’L ACAD. SCI. e5635 (2017); *Sperm Mutations Rate Varies Between Fathers*, Wellcome Sanger Inst. (Dec. 14, 2015), https://www.sanger.ac.uk/news_item/sperm-mutation-rate-varies-between-fathers/ [<https://perma.cc/PC5L-RS4C>]; Heidi Ledford, *Air Pollution Causes Sperm Mutations*, NATURE (Jan. 13, 2009), <https://www.nature.com/news/2008/080113/full/news.2008.439.html> [<https://perma.cc/V5R5-2MV6>]; Marc A. Beal et al., *From Sperm to Offspring: Assessing the Heritable Genetic Consequences of Paternal Smoking and Potential Public Health Impacts*, 773 MUTATION RSCH., July 2017, at 26.

As described above, sperm donors lie on numerous occasions. Many people lie on their resumes or to their partners; even when there is reliance on those lies, they are rarely held to task, even after the fact.¹¹⁰ Despite the expansive nature of the US Federal False Statement law, the law remains limited to situations not covered herein.¹¹¹ It is unclear, however, what legal liability may exist that would allow a parent of a donor child to sue the lying donor.

There are some other limited situations where fraudulent misrepresentation is illegal, but those are often limited to misrepresenting whether you are licensed to practice medicine or law. Even when there is no specific law in a jurisdiction related to these professions, there are often other deceptive trade practices and consumer protection laws that would criminalize these misrepresentations. In some jurisdictions, it is illegal to claim to be another real individual. In some situations, fabricating your identity to obtain remuneration is also illegal. These situations can, but need not, encompass situations related to misrepresentation on an intake form for sperm donation. Moreover, in the available case law vis-à-vis sperm donors, the donor is not usually the defendant in a case of fraudulent misrepresentation; rather, it is the deep-pocketed clinic. Unless the donor is entirely unfit to be a donor, it is unlikely that a charge of fraudulent misrepresentation would hold up. The donor donates regardless of who chooses their sperm, so there is no reliance in this case and therefore, the contract would likely be entered into regardless of whether the donor was who they said they were, or someone else.

110. Mark Wexler, *Successful Resume Fraud: Conjectures on the Origins of Amorality in the Workplace*, 12 J. HUMAN VALUES, 137, 137-52 (2006); see generally, Steven R. Morrison, *When is Lying Illegal? When Should It Be? A Critical Analysis of the Federal False Statements Act*, 43 J. MARSHALL L. REV., 111 (2009); Linda Ficht & Julia Levashina, *When Lying, Cheating and Stealing Isn't Necessarily Illegal: The Need to Adopt A Commercial Fraud Standard In Employment Law Cases*, 290 S. L. J. 289 (2011).

111. 18 U.S.C. § 1001 (limited to statements “. . . in any matter within the jurisdiction of any department or agency of the United States”).

Recent bills in states like Colorado,¹¹² California,¹¹³ Indiana,¹¹⁴ Arizona,¹¹⁵ Texas,¹¹⁶ Arkansas,¹¹⁷ and Florida¹¹⁸ provide for civil penalties in the case of fertility fraud, but they don't always explain just exactly what that entails and often focus on the doctor, not the non-doctor donor. Nebraska,¹¹⁹ Iowa,¹²⁰ Ohio,¹²¹ New York,¹²² Oregon¹²³, Washington,¹²⁴ and Pennsylvania¹²⁵ are similarly considering fertility fraud laws.

A. Sperm Donor Manipulating DNA

CRISPR has raised numerous ethical, legal, and social concerns with most of the considerations falling along two axes: (1) whether the editing of the DNA is therapeutic or an enhancement¹²⁶ (the definitions of which are fuzzy¹²⁷); and (2) whether the editing is to the germ line¹²⁸ or to the somatic cells.

112. Saja Hindi, *It's now a crime for Colorado fertility doctors to impregnate patients with their own sperm* DENVER POST, July 6, 2020.

113. California Code, Penal Code - PEN § 367g.

114. SB 174, 121st Gen. Assemb., 1st Reg. Sess. (Ind. 2019).

115. *Arizona governor signs online dating, fertility fraud bills*, AP (Mar. 25, 2021), <https://apnews.com/article/arizona-phoenix-health-legislation-lawsuits-f29933dbe335d3dec9ca76219a00c6c9> [<https://perma.cc/K7WY-TDB6>].

116. SB 1259, 86th Leg., (Tex. 2019) (Senate Bill 1259 makes it illegal to inseminate a person without their complete consent—supposedly that would include cases of fraudulent misrepresentation, but the onus is on the medical practitioner, not the donor).

117. SB 474, 93d Gen. Assemb., Reg. Sess. (Ark. 2021).

118. HB 1287, 2021 Leg., Reg. Sess. (Fla. 2020).

119. LB 748, 2020 Leg., Reg. Sess. (Neb. 2020). *See also* Paul Hammel, *Fertility fraud bill would punish doctors who illicitly use their own sperm*, OMAHA WORLD HERALD (January 30, 2020), https://omaha.com/state-and-regional/fertility-fraud-bill-would-punish-doctors-who-illicitly-use-their-own-sperm-to-inseminate-patients/article_95a7228c-a5fc-52e9-8f67-5318c7e7affc.html [<https://perma.cc/HSSZ-YHPC>].

120. SB 529, 89th Gen. Assemb., Reg. Sess. (Iowa 2021).

121. Susan Tebben, *Fertility fraud victim wants punishment put in Ohio law*, OHIO CAPITAL JOURNAL (Mar. 22, 2021), <https://ohiocapitaljournal.com/2021/03/22/fertility-fraud-victim-wants-punishment-put-in-ohio-law/#:~:text=The%20bill%20creates%20a%20third,%2C%E2%80%9D%20ac-cording%20to%20the%20bill> [<https://perma.cc/8A2N-G46G>].

122. Assemb. A00718A 2021, 2021 Leg., Reg. Sess. (N.Y. 2021).

123. HB 3362, 81st Leg. Assemb., Reg. Sess. (Or. 2021).

124. SB 5348, 67th Leg., Reg. Sess. (Wash. 2021).

125. HB 504, 2021 Gen. Assemb. (Pa. 2021).

126. National Academies of Sciences, Engineering, and Medicine, *HUMAN GENOME EDITING: SCI., ETHICS, AND GOVERNANCE* 137 (National Academies Press 2017).

127. Dov Greenbaum & Laura Y. Cabrera, *Editorial: ELSI in Human Enhancement: What Distinguishes It From Therapy?*, 11 FRONTIERS IN GENETICS (2020).

128. Eliot Marshall, *Moratorium Urged on Germ Line Gene Therapy*, 289 SCIENCE 2023 (2000); Elisabeth Hildt, *Human Germline Interventions—Think First*, 7 FRONTIERS IN GENETICS 81 (2016); David Baltimore et al., *A Prudent Path Forward for Genomic Engineering and Germline Gene Modification*, 348 SCIENCE 36, 38 (2015); Henry I. Miller, *Germline Gene Therapy: We're Ready*, 348 SCI. 1325

Enhancement is seen as ethically more problematic than therapeutic efforts, as the ethical cost-benefit analysis consistently weighs heavier on the side against engineering, given the potential for unforeseen side effects and externalities. Similarly, it is ethically more problematic to edit the germ line, (i.e., the DNA that is passed down from parent to child indefinitely) than to edit a somatic cell line. This is because editing the somatic cell line results in an alteration of only the individual undergoing gene therapy but not their offspring; in other words, because the mutation dies with the individual undergoing the therapy.

B. The CODIS System

The Combined DNA Index System (CODIS) is the name of the FBI database that is used for generating DNA fingerprints and profiles.¹²⁹ The database was established by the Federal DNA Identification Act of 1994 and has been subsequently updated.¹³⁰

In its current iteration, there are twenty CODIS STR markers represented by the following codes: SF1PO, D3S1358, D5S818, D7S820, D8S1179, D13S317, D16S539, D18S51, D21S11, FGA, TH01, TPOX, vWA, D1S1656, D2S441, D2S1338, D10S1248, D12S391, D19S433, D22S1045.¹³¹ Each CODIS marker represents unique locations (loci) spread out somewhere within the three billion bases (six billion total, as we each have two copies of our genetic code, one from each parent) of the human genome.¹³²

At each of these loci, there are highly polymorphic short tandem repeats (STRs) represented as a pair of numbers within the CODIS databases.¹³³ Those two numbers reflect the number of times a short stretch of genetic code is repeated at the particular location in the genome, or locus (pl. loci). As we each inherit two genomes, one from our father and one from our mother, each locus could have the short sequence repeated differently. For example, the STR D7S820 is located on the seventh (out of twenty-three)

(2015); Arthur Caplan, *Getting Serious About the Challenge of Regulating Germline Gene Therapy*, 17 PLOS BIOLOGY (2019).

129. Mark A. Jobling & Peter Gill, *Encoded Evidence: DNA in Forensic Analysis*, 5 NATURE REVIEWS GENETICS 739, 739–51 (2004).

130. 34 U.S.C. § 40702.

131. D.R. Hares, *Selection and implementation of expanded CODIS core loci in the United States*, 17 FORENSIC SCI. INT. GENETICS 33–34 (2015).

132. J. Craig Venter et al., *The Sequence of the Human Genome*, 291 SCI. 1304, 1304–51 (2001).

133. Karen Norrgard, *Forensics, DNA Fingerprinting, and CODIS*, SCITABLE BY NATURE EDUC. (2008), <https://www.nature.com/scitable/topicpage/forensics-dna-fingerprinting-and-codis-736/> [https://perma.cc/H928-F2JK].

chromosome. At this locus, each individual can have the genetic sequence GATA repeated between five and sixteen times due to biology that is beyond the scope of this paper. An individual might inherit a genome from a father with the sequence at D7S820 repeated eight times and a different sequence from their mother wherein they inherit ten repeats of the GATA sequence. In the database, they will be represented as such: D7S820: 8,10.¹³⁴ A collection of twenty of these loci and the number of the repeats at the loci is the genetic fingerprint or genetic profile. In some instances, the individual will have inherited the same number of repeats from both mom and dad. In practice, sometimes those repeats are represented as fractions due to the methods by which the repeats are calculated (again, beyond the scope of this paper).

C. Sperm Donor Manipulating Non-Coding DNA

DNA can be broadly divided into coding and non-coding DNA.¹³⁵ Coding DNA is predominantly what would be referred to colloquially as genes. These are the stretches of DNA that result in what is one's phenotype through the translation of genomic information into proteins. Mutations or other alterations in coding DNA can have significant effects on the individual for better or for worse.

The vast majority of DNA is non-coding. Somewhere on the order of 98% of all DNA in the human genome is non-coding. Decades ago, it was thought that the non-coding DNA was junk,¹³⁶ evolutionary artifacts, and garbage left over from millennia of genetic progress. But today, non-coding does not necessarily mean junk.¹³⁷ As we have gained more knowledge, we have gained a greater appreciation for the value of at least some of this non-coding DNA.¹³⁸

But even with this new understanding, there is still a broad consensus that vast stretches of DNA (up to 20% of the genome) are almost effectively

134. *Id.*

135. Svetlana A Shabalina & Nikolay A Spiridonov, *The Mammalian Transcriptome and the Function of Non-Coding DNA Sequences*, 5 *GENOME BIOLOGY* 105 (2004).

136. Faye Flam, *Hints of a Language in Junk DNA*, 266 *SCI.* 1320 (1994); Wojciech Makalowski, *Not Junk After All*, 300 *SCI.* 1246 (2003); Jonathan Wells, *Not Junk After All: Non-Protein-Coding DNA Carries Extensive Biological Information*, *BIOLOGICAL INFO.: NEW PERSPECTIVES* 210–231 (2013); Dov Greenbaum, *Junk?*, *MBB YALE*, <http://bioinfo.mbb.yale.edu/mbb452a/projects/Dov-S-Greenbaum.html>.

137. Dov Greenbaum & Mark Gerstein, *Illuminating the Genome's Dark Matter*, 163 *CELL* 1047 (2015); Dov Greenbaum, *Junk DNA*, in *DICTIONARY OF BIOINFORMATICS AND COMPUTATIONAL BIOLOGY* (2014).

138. Elizabeth Pennisi, *ENCODE Project Writes Eulogy for Junk DNA*, 337 *SCI.* 1159 (2012); Christian Biémont, *A Brief History of the Status of Transposable Elements: From Junk DNA to Major Players in Evolution*, 186 *GENETICS* 1085 (2010).

useless.¹³⁹ Like evolutionarily random power cords that have accumulated in our genomic junk drawers,¹⁴⁰ any variation within this 20% has absolutely no known effect on the health of the individual. Within these stretches of DNA lie the STRs that are employed by the CODIS system and are used to establish identity¹⁴¹ and paternity.¹⁴² Whatever concerns we may have as a society vis-à-vis the genetic manipulation of DNA, we would likely have the least amount of concern for manipulation of this DNA.

With that said, the CRISPR system is not infallible, and any time DNA is manipulated, even with the surgical efficiency of CRISPR, we run the possibility of unintended changes to other areas of the genome. Some of those changes carry the likelihood of creating actual damage.¹⁴³

IX. YOUR GENOME: THE OG BIG DATA

Extrapolating from information regarding HIV status of a sexual partner,¹⁴⁴ we can assume that in balancing the privacy and anonymity of the donor over the desire of the donor-conceived child to know their parents, we would fall in favor of knowledge for the child, if that knowledge provides important health information. However, with the advent of easily accessible genetic testing, the identity of the donor is no longer that much more informative vis-à-vis the mineable health information than the genetic information that can now be easily and cheaply culled from relatively cheap commercial genetic sequencing. This is especially the case if a donor values their privacy and is unwilling to disclose the nature and extent of their family medical history even if they choose to not remain anonymous.

Barring those jurisdictions that regulate whether a donor can sell their sperm, there is little, if any, interest by the state in controlling what a man

139. Emily Mortola & Manyuan Long, *Turning Junk into Us: How Genes Are Born*, 109 AM. SCIENTIST 174 (2021); Pennisi, Elizabeth. "ENCODE project writes eulogy for junk DNA." (2012): 1159-1161; Doolittle, W.F., Brunet, T.D.P. On causal roles and selected effects: our genome is mostly junk. *BMC Biol* 15, 116 (2017)

140. *But, c.f.*, Kaye *supra* note 20.

141. Sara H. Katsanis & Jennifer K. Wagner, *Characterization of the Standard and Recommended CODIS Markers*, 58 J. OF FORENSIC SCI. S169 (2013).

142. CATHERINE THERESE ALLOR, THE CHARACTERIZATION OF VARIANT ALLELES AT THE 13 CODIS STR LOCI FOR USE IN PATERNITY DISPUTE RESOLUTIONS (2004).

143. Contrast Yanfang Fu et al., *High-frequency Off-Target Mutagenesis Induced by CRISPR-Cas Nucleases in Human Cells*, 31 NATURE BIOTECHNOLOGY 822 (2013), with Benjamin P. Kleinstiver et al., *High-Fidelity CRISPR-Cas9 Nucleases With No Detectable Genome-Wide Off-Target Effects*, 529 NATURE 490 (2016) (in any event the technology is advancing daily); Matthew A. Coelho et al., *CRISPR GUARD Protects Off-Target Sites From Cas9 Nuclease Activity Using Short Guide RNAs*, 11 NATURE COMMUN 1 (2020); Muhammad Naem et al., *Latest Developed Strategies to Minimize the Off-Target Effects in CRISPR-Cas-Mediated Genome Editing*, 9 CELLS 1608 (2020).

144. *Limits on Confidentiality*, HIV.GOV, <https://www.hiv.gov/hiv-basics/living-well-with-hiv/your-legal-rights/limits-on-confidentiality> [<https://perma.cc/6JP7-U4VL>].

does with their sperm, provided they are not harming anyone else. On the other hand, what a woman does with sperm can be problematic—for instance, in cases of sperm theft.¹⁴⁵

We are left with the possibility that a donor desiring anonymity can legally—and perhaps even ethically—genetically manipulate their sperm (even if that means manipulating the germ line) if there is no perceivable harm to any eventual child. While this is a suboptimal situation, it seems wrong. Nevertheless, it is hard to extract the visceral concerns that we might have with it. This final chapter will attempt to do just that.

A. *The Human Genome Belongs to All of Us*

The human genome is a molecular warehouse of knowledge and factual information. The genome is comprised of sequences of molecules that when decoded, outline the genetic blueprints of mankind and provide other information that can be used to extract knowledge.

The human genome is a highly dense storage medium, holding 215 petabytes of data per gram of DNA molecule.¹⁴⁶ This has been estimated to be 420 billion times that of traditional storage media.¹⁴⁷ Within its molecular chains, DNA stores data about our past, our present, and our future, even describing human evolution,¹⁴⁸ human migration,¹⁴⁹ human disease,¹⁵⁰ and

145. Revital Hovel, *Israeli Woman Found Guilty of 'Sperm Theft,' Ordered to Pay \$31,000*, HAARETZ (Mar. 12, 2013), <https://www.haaretz.com/premium-woman-to-pay-31k-for-sperm-theft-1.5296697> [<https://perma.cc/2RN8-5FKP>]; Chris Pleasance, *Mother In Court Accused of Stealing Her Ex-Boyfriend's Frozen Sperm Before Using It To Get Pregnant To Spite Him For Breaking Up*, DAILYMAIL (Aug. 11, 2015, 5:00 PM), <https://www.dailymail.co.uk/news/article-3194225/Mother-court-accused-stealing-ex-boyfriend-s-frozen-sperm-using-pregnant-spite-breaking-up.html> [<https://perma.cc/9QCS-SE4U>]; Russell Goldman, *Louisiana Man Accuses Ex-Girlfriend of Stealing His Sperm*, ABC NEWS (Mar. 1, 2013, 1:26 PM), <https://abcnews.go.com/US/man-accuses-girlfriend-stealing-sperm/story?id=18631048> [<https://perma.cc/FUX8-5PZU>]; Mary Dejevsky, *Woman Sued for 'stealing' sperm*, INDEPENDENT (Nov. 24, 1998, 01:02), <https://www.independent.co.uk/news/woman-sued-stealing-sperm-1187028.html> [<https://perma.cc/3U6C-H9YU>]; *Man Can Sue Woman For Sperm Theft Distress*, ASSOCIATED PRESS (Feb. 24, 2005), https://canadiancrc.com/Newspaper_Articles/AP_Man_can_sue_sperm_theft_distress_24FEB05.aspx [<https://perma.cc/V6C6-B6BV>].

146. John Cumbers, *DNA Data Storage is About to Go Viral*, FORBES (Aug. 3, 2019, 10:18am EDT), <https://www.forbes.com/sites/johncumbers/2019/08/03/dna-data-storage-is-about-to-go-viral/#11e9d6847721> [<https://perma.cc/2DRS-4GPD>].

147. Shufang Zhang et al., *A High Storage Density Strategy for Digital Information Based on Synthetic DNA*, 3 BIOTECH 341, 342 (2019).

148. Hedi Hegyi et al., *Structural Genomics Analysis: Characteristics of Atypical, Common, and Horizontally Transferred Folds*, 47 PROTEINS: STRUCTURE, FUNCTION, & BIOINFORMATICS 126, 126–41 (2002).

149. Dov Greenbaum & Mark Gerstein, *Human History, Human Genomes*, 174 CELL 1043, 1043–44 (2018).

150. Michael J. Bamshad et al., *Mendelian Gene Discovery: Fast and Furious With No End in Sight*, 105 THE AM. J. OF HUM. GENETICS 448, 448–455 (2019).

human potential.¹⁵¹ In each human, there are enough DNA molecules to stretch from Earth to Pluto and back, a distance of ten billion miles.¹⁵²

Factual information, genetic or otherwise, falls outside the scope of ownership granted by most intellectual property rights¹⁵³ (barring trade secrets, with caveats). As such, the nature of one's ownership—and as a corollary one's control over the factual data relating to them (collected ad nauseum by technological devices and online platforms)—is still not certain.

The recent enactment of the European General Data Protection Regulations (GDPR) created a novel way to appreciate that ownership of data.¹⁵⁴ It granted data collectors some form of control over data in that they could modify and commodify it, while simultaneously granting rights to the originators of that data, i.e.—you. Under the GDPR, everyone retains numerous rights, such as the right to access data,¹⁵⁵ the right to rectification,¹⁵⁶ the right to be forgotten,¹⁵⁷ the right to the restriction of data processing,¹⁵⁸ the right to notification,¹⁵⁹ the right of data portability,¹⁶⁰ and the right to object to uses of the data,¹⁶¹ among other rights.

How can the law claim to allow data collectors to retain control over the data yet impose so many obligations to you, the source of the data? The GDPR creates a distinction between data ownership and data custody.¹⁶² The masses of individuals from which the data is collected retain some form of ownership over their data. Even once it is collected and extracted, the data

151. Amit Bar Sela et al., *Sports is Fleeting, But Genetics is Forever: Some Legal and Ethical Implications of Genetics in College Sports*, 16 VA. SPORTS & ENT. L.J. 1, 1 (2016); Dov Greenbaum, *If You Can't Walk the Walk, Do You Have to Talk the Talk: Ethical Considerations for the Emerging Field of Sports Genomics*, 13 AM. J. BIOETHICS 19, 19–21 (2013); Dov Greenbaum, *Introducing Personal Genomics to College Athletes: Potentials and Pitfalls*, 12 AM. J. BIOETHICS 45, 45–47 (2012).

152. Kristen Weir, *20 Things You Didn't Know About . . . DNA*, DISCOVER (June 12, 2011, 7:00 PM), <https://www.discovermagazine.com/the-sciences/20-things-you-didn't-know-about-dna> [<https://perma.cc/4AJJ-SHWC>].

153. Dov Greenbaum, *The Database Debate: In Support of an Inequitable Solution*, 13 ALB. L. J. SCI. & TECH. 431, 431 (2002); Dov Greenbaum, *Are We Legislating Away Our Scientific Future? The Database Debate*, 2 DUKE L. & TECH. REV. 1, 1–15 (2003).

154. European Parliament and Council of European Union Regulation 2016/679, 2016 O.J. (L. 119/1).

155. *Id.* at art. 15 (right of access by data subject).

156. *Id.* at art. 16 (right to rectification).

157. *Id.* at art. 17 (right to erasure ('right to be forgotten')).

158. *Id.* at art. 18 (right to restriction of processing).

159. *Id.* at art. 19 (notification obligation regarding rectification or erasure of personal data or restriction of processing).

160. *Id.* at art. 20 (right to data portability).

161. *Id.* at art. 21 (right to object).

162. Dov Greenbaum, *On Big Data, Patent Law, and Global Warming*, CTECH (Dec. 13, 2019, 11:14), <https://www.calcalistech.com/ctech/articles/0,7340,L-3775695,00.html> [<https://perma.cc/P62C-UZF2>].

still belongs to the individuals from whom it was collected; that seems to be the purpose of the aforementioned rights granted by the GDPR. The data collectors, then, are custodians not true owners of the data. In return for custodial rights over the data—to extract, commodify, modify, sell or manipulate as they choose—they retain certain obligations to you, the individual and the source.

We can import this idea from data in general to the original source of big data: your genome. Simplistically, each sperm donor owns their sperm completely and in its entirety. They can do with it as they please, provided no one else is harmed. In many jurisdictions, your personal rights over sperm are even greater than other aspects of your body in that you can sell it¹⁶³ (whereas you cannot sell most other body components even if they also regenerate¹⁶⁴).

However, despite our ownership over our physical sperm and the physical DNA they hold, we are each only a custodian with regard to the human genome information contained within each and every spermatozoa. To wit, while each sperm cell contains a unique copy of a human genome, we do not own the information encoded in that genome; instead, we share it with our extended family, we are merely custodians over the data for the collective humanity.

Like data under the GDPR, as custodians of our genome, we are granted many different uses of our genome. These uses include the right to live a natural life, the right to procreate with whom we want (at least in most modern societies and jurisdictions) and as we see fit, and the right to do so as often as we like, even as that procreation introduces new variability into the human genome, as it always does.

However, as custodians, we are not full owners of that genome, and society places limits on what we can do with our genomes. For example, society currently allows for somatic cell line gene editing for primarily therapeutic uses. Those are the “unnatural” alterations that we are currently allowing ourselves as a society.

But, as a society, we have also collectively determined that all other types of genomic editing is currently verboten. However, as society evolves, or devolves, the nature of the dispensations allowed vis-à-vis genomic manipulation could change. For example, in the future, germ line editing and/or genomic enhancement could become accepted by society, and our rights and obligations as custodians will change accordingly to accommodate such

163. G.K. Michalopoulos & M.C. De Frances, *Liver regeneration*, 276 *Sci.* 60–66 (1997).

164. A.L. Friedman, *Payment for living organ donation should be legalized*, 333 *BMJ* 746–748 (2006).

social change. We could also conceivably contract those rights, limiting with whom we can “naturally” procreate, or limiting the number or even type of children we can create.¹⁶⁵

More specifically, sperm donors have the right to provide their sperm for remuneration in most jurisdictions to help others procreate. In fact, if the sperm is provided naturally—even in a donor capacity—and not frozen or via a third party, society does not typically like getting involved in regulating the process.

However, when an individual chooses to modify their germ line via genetic engineering, they leave the realm of ownership and enters the realm of that of a custodian. In these cases, the sperm donor may be in violation of the custodial obligations over the genome, as currently defined by society.

Of course, as society defines the nature of the custodial relationship, whether or not a sperm donor can manipulate CODIS markers under the custodian contract, depends on how society sees the CODIS loci. To wit: are these loci, non-coding DNA unrelated even remotely to phenotype, parts of the human genome that we need to hold in trust for future generations and preserve as best as possible without modification, or are these parts of the human genome essentially junk, useless to humanity, and modifiable under our custodial contract with society? We do not yet know.

Thus, depending on how this is eventually parsed out, CRISPR-ing the CODIS markers in sperm may or may not be a morally abhorrent action. This mindset can help answer longstanding concerns with other areas of genetic engineering, as well. For example, as a society, we often see troublesome cases when parents with disabilities specifically choose to employ genetic engineering to have a child with the same or similar disability, and yet, we would not begrudge those same parents to seek out ways to genetically engineer their child, to employ ART to have a child without disabilities, or even to have a child with disabilities, albeit naturally, without employing any ART.¹⁶⁶

Consider a concrete example: deaf couples have children all time without society imposing any restrictions on them, perhaps by arguing that no deaf parent has the right to create a child that will likely also be differently

165. Sara Weinberger, Sharon Nakar, & Dov Greenbaum, *They Chose . . . Poorly: A Novel Cause of Action to Discourage Detrimental Genetic Selection*, 43 AMERICAN JOURNAL OF LAW & MEDICINE 107 (2017).

166. Dov Greenbaum, *Anti-Vaxxers and Autism: Disability Culture vs. Ignorance*, CTECH (Nov. 11, 2019, 09:57), <https://www.calcalistech.com/ctech/articles/0,7340,L-3774787,00.html> [<https://perma.cc/X4CU-GSA3>].

abled, i.e., deaf. Yet, when a lesbian couple employed ART to specifically have a deaf child, there was a social backlash.¹⁶⁷

What is the distinction that divides the viscerally disfavored from the allowable? Like we proposed above, it is the dichotomy between ownership and custodianship. We own our bodies and as a society, we allow for the use of those bodies to naturally procreate and to do what we want with our gametes. There are sparingly few jurisdictions that (still) place limits on the people with whom we can have children. As such, every time consenting adults choose to procreate, they are creating a new human with new genetics that have likely never existed before. They are in essence playing God, and yet no one calls it that. Drilling even deeper, every major decision that a parent makes in the life of a child, both in utero and after birth, can have huge repercussions on that child's future, and yet only some of the only decisions that society deems verboten are those relating to genetic engineering.

Ultimately, the distinction comes allowable and currently unallowable arguably comes down to this: one employs sperm, the other employs the genome. Our bodies are our own to do (mostly) as we please. The same goes for our gametes. What one does with sperm under 'natural' conditions is currently unregulated. You have full ownership over your sperm. What you do with genomic information, e.g., with sperm through ART, is regulated by society—as one is only a custodian. Progressive liberal society does not aim to limit what we can do with these physical things. In contrast, our genomes are, to paraphrase a famous advertisement, not something we own, just something we look after for the next generation.¹⁶⁸ What you do with sperm under 'natural' conditions is currently mostly unregulated, if at all. You have full ownership over your sperm. What you do with genomic information, however, becomes regulatable by society as you are only a custodian here, protecting it and maintaining it for the next generation.

167. M. Spriggs, *Lesbian Couple Create a Child Who is Deaf Like Them*, 28 J. OF MED. ETHICS 283, 283 (2002); J. Savulescu, *Deaf Lesbians, "Designer Disability," and the Future of Medicine*, 325 BMJ 771, 771–773 (2002); K.W. Anstey, *Are Attempts to Have Impaired Children Justifiable?*, 28 J. OF MED. ETHICS 286, 286–288 (2002); Kristen R. Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L. J. 299, 299 (2008); Dov Fox, *Reproductive Negligence*, 117 COLUM. L. REV. 149, 149 (2017); M. Häyry, *There is a Difference Between Selecting a Deaf Embryo and Deafening a Hearing Child*, 30 J. OF MED. ETHICS 510, 510–12 (2004); Steven Emery et al., *Whose Deaf Genes Are They Anyway? The Deaf Community's Challenge to Legislation on Embryo Selection*, 10 SIGN LANGUAGE STUD. 155, 155–169 (2010); Silvia Camporesi, *Choosing Deafness with Preimplantation Genetic Diagnosis: An Ethical Way to Carry on a Cultural Bloodline?*, 19 CAMBRIDGE Q. HEALTHCARE ETHICS 86, 86 (2010); T.F. Murphy, *Choosing Disabilities and Enhancements in Children: A Choice Too Far?*, 18 REPROD. BIOMEDICINE ONLINE, 43, 43–49 (2009).

168. *The Next Chapter of the Generations Campaign*, PATEK (Sept. 10, 2019), <https://www.patek.com/en/company/news/generations-campaign> [<https://perma.cc/RFW9-VMCF>].